**Beyond Stigmas: Navigating Palliative Care**

**SPEAKERS**

Melissa Chadwick, Narrator, Dr. Bill Evans

**Narrator** 00:02

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**Dr. Bill Evans** 00:23

so welcome to the cancer assist Podcast. I'm Dr. Bill Evans, your host, and today we're talking to Melissa Chadwick and Melissa is a nurse working in the palliative care field in the area of Hamilton and we're delighted to have her but before I formally introduce her and asked her to tell us a little bit about herself, I just wanted to remind our listeners that the cancer assist podcast is brought to you by the cancer Assistance Program, here in Hamilton and the cancer Assistance Program provides a variety of free services to patients who need those services include free rides, equipment, loans, nutritional and incontinence supplies, amongst a number of other supports for our cancer patients. And one of those supports is this podcast, which is made possible by generous donations from individuals in the Hamilton community. And we hope that by learning more about cancer and its causes, the current treatment approaches, and the supports that are available from various members of the healthcare community, and volunteer organizations that it will just make the challenge of dealing with cancer a bit easier. So welcome, Melissa, I'm delighted to have you and to have an opportunity to talk about some of the things you know about palliative care because I gather from our little pre conversation, your experience at multiple levels, dealing with palliative care issues, as well as some some personal experiences that probably helped shape your thinking and, and probably your drive to be involved in this particular area. So maybe you just tell us a little bit, a little bit about yourself to start off so our listeners can get a bit to know you and then we'll dive into the palliative care topic.

**Melissa Chadwick** 02:09

Awesome. Thanks so much for having me here today. This is my first podcast. So I am not too nervous, but I you know, it's just a conversation. So I've got this sort of microphone in my face, but that's okay. So I've been I, I'm my story sort of is is that I feel like as a as a nurse, palliative care picked me when I was young, I had a Wilms tumor, which is a child who had cancer, and I lost my left kidney and adrenal gland in 1979. To that and had 18 months of chemotherapy and radiation at McMaster and then over at the Henderson. And very, very fortunately have survived that experience to be here today. And I have two healthy kids that are on their way that we've got one at the University of Waterloo and one that's looking to go to share it in I just got actually just got married in September to my wife, Tracy. So it's super awesome. And I really feel very fortunate. But I went to school in Toronto when I went to university, and my dad was sick in the summer, and we still went away on our family vacation. And I actually had to drive him back from that. And he was a direct admit to Joseph Brant Hospital, he had a large softball sized tumor in a sigmoid colon, and metastatic disease. So where the disease had spread throughout his body. And that was really hard because I had just started nursing school. And my dad unfortunately passed away about five weeks later. But what that translated, I think to for me with the work that I do is that I'm honoring that legacy. Every day sort of in and out, we had some good help and supports, it was a very, very unfortunate situation. My dad was young 49, you know, two kids 16 And 19 kind of thing. And we weren't really prepared for what was going to happen. You know, we had like I said, Good familial supports really good supports at the hospital, my dad passed away in hospital, and they had a brochure, it said, my loved one is dying, what do I do? What do I expect? And I, I use a version of that even now to this day to help people. But the more time I've spent working in palliative care, and I've worked at hospice, and I've done visiting nursing, and I've worked at home care, and I just find that more and more, we're talking about being hopeful and talking about planning I find with folks now. So even in my own family, I sort of say to my mom, like, if you want we want to do this, I want to stick with you with that, but what do we what does it look like if it's changing? Because you know, we've got aging parents or you know, my husband has Parkinson's and things like that. So what is it kind of what are things kind of looking like so again, sort of less talking about death and dying, but what what are your goals? What do you want to look at? And so I've been, I find that that things are changing a bit and we're helping caregivers more also ask the questions back to their physicians and things like that. I also got to work at the cancer center, which was a really great experience. I was there for about nine months and I

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I that was sort of my break from death and dying a bit. And that but I found that when I was there, and I knew about cancer Assistance Program at the time when it was in the little, little house, you know, there were some great services and connections there. So I think we'll talk about some of those things and palliative care today with you here, Bill. So so as you say, really, the palliative care chose you. Yeah, absolutely. And shaped your thinking. And those experiences, I think that's true for many who are drawn to work in the cancer field is that they had a personal experience and, and maybe it wasn't a good cancer experience, and they want to be in the field so they can make it better. Or maybe they saw things that just sort of resonated with him in terms of the empathy and the caring the supports of individuals that drew something out of them, that was part of their need being palliative care, I think there's a lot of misconceptions about it. And I really liked you to talk about that. And that because the term itself means to many people, I think it's the end of life, and maybe the very last bit of life. And, and really, when you're trying to palliate somebody you're trying to make

**Dr. Bill Evans** 06:06

the things they're experiencing better. And that could be at any point along the trajectory of an illness and cancer, heart disease, or whatever. And we've somehow got to explode this idea that palliative care is just end of life activities, right? Yeah,

**Melissa Chadwick** 06:21

I blame sometimes television and movies for stuff like that. So the idea of what death is actually like, and so sometimes we have this idea that death occurs, I can remember watching a TV show, and they sort of came out and said, You know, I'm very sorry, there's nothing more we can do. You know, and, and we sort of have this I think narrative in our head, sometimes when we hear language like that, but and where palliative care came from. In the UK, the Dame Cicely Saunders was sort of the the grandmother of that movement. And the story I tell about her whether I've got it right or not, but she was a social worker, I think to begin with, or a nurse, I can't totally remember. And she was working in the hospital. And that's when you had the private rooms down at the end of the hallway. And that's where they put people to die. And there was nothing more we could do. And people would die, you know, sort of in a not very nice way. And this is like in the late 60s 70s, very beginning of the 70s. And then she hurt herself got reassigned. I don't know what happened, she end up working at like a Veterans Hospital. And she found people were outside. And they were eating what they wanted to. And they were getting their pain medication and symptom medication regularly every four hours, right, which was how those medications work, military, some sort of, but people had much better experiences with symptoms, their death was much more manageable than this sort of we we've done everything we can we can't Down you go and close the door. So and then that sort of and then she went back to medical school to become a physician. And so it was the was the birth mother, I think of that movement. Then that came over to Canada in the 70s. And it's about Dr Belford mount, who started that and who actually coined the term I believe pellier which means to cloak or to wrap around. And that's the thing that I think that when when you hear the word palliative care, people think, Oh, I'm not terminal, or they get almost taken aback or scared or, or things happen when they hear that. But it can be you can have a palliative approach to your care for 10 years, you could have it for the whole time of that from time of diagnosis is what they say if we use that approach, and talk to people about what their goals of care are, that they did a study, like I said Harvard did a study and when we do that approach from the get go, and that could be oncology, or cancer care. It could be cardiology, like heart, heart stuff, it could be dementia like gerontology, nephrology or kidney folks that people have less pain and symptom management issues. They have less anxiety and depression, and they live longer, on average about three months longer. But I think that in conversation, it's important to have upfront because what do people actually want, because sometimes they'll just go along with what the medical system says or what their family thinks. And we have this idea that people give up, I you know, sometimes I'd love to write a paper or talk unpack about that, you know, I live here that like, Oh, someone's always given up or whatever, and like, death is natural. And so if someone has sort of checked all the things that they want to do on their list, and they're we're moving towards the end of their story, it's not giving up it's this nice, graceful sort of exit like this, you know, kind of thing. But we have these ideas sometimes about oh, they're not fighting anymore. Like again, militaristic kind of ideas. We're not, we're not fighting anymore, they're giving up and things like that or fought a courageous battle. And that's not to diminish that, you know, people with life limiting illnesses aren't going through something or being resilient or suffering or those kinds of things, but it's not a loss. I want to go around to the funeral homes and see who writes the obituary sometimes just maybe just change the language a little bit to bring it into 2024. Because not to say those things aren't honest or authentic. But, you know, you ever see like a really good obituary that's written in sort of a bit of a different way. And it's more of that, about that person and their life and the celebration, not about how they died. And I think that would make a difference, right? If we sort of had a more death, positive view in society, or

**Dr. Bill Evans** 10:24

death avoidance culture, for sure, absolutely. It was interesting when you ask patients cancer patients anyway, what they most value when you're assessing like new drugs and things like that. Also, they want longer life, and they want better quality life. And you know, it's interesting just in what you were describing what palliative care does, it not only makes the quality of life better by managing the symptoms much better, but it also extends life. And that's one of the surprises. You mentioned, the Harvard study, there's other studies that have come out with lung cancer with halogen, sort of aggressive supportive care measures or palliative measures, versus just the usual care and a significant difference in survival. And I think that's a real surprise to the medical community. And it's like a lot of things that we know that we don't really action very well, partly because you're busy. There's not enough time, there's so many patients, treatments got so complex. So we have to devote all of our energies into doing that. And some of these quote softer things kind of get pushed to the side or forgotten about. And we focus on sort of the technological and logistic aspects of care, without thinking about how we're really truly supporting people and think about how can we optimally integrate supportive care, palliative care, across the continuum, they really should interlock. And maybe the amount of palliative care supportive care, at the beginning of an illness take lung cancer is relatively modest, because maybe there isn't much shortness of breath or some cough, but no pain. But as the disease progresses, some of those symptoms might come to the fore. But if the palliative medicine supportive care physician, or nurse or team was involved, it wouldn't have much to do at the beginning, except establishing a relationship with the patient with the family and getting to know them. And then as the trajectory goes along, and they start developing more symptoms, they're better managed. And palliative medicine physicians, nurses and teams are so much better managing symptoms, and our most oncologists, you know, not to denigrate what they do and how good or bad they are. They're, they're really busy. And sometimes they just don't have enough attention to some of those details. Yeah.

**Melissa Chadwick** 12:38

And that's what I mean, it's sometimes it's that those pieces that we want to like, again, sort of walk alongside and we want to build the capacity of, of the, like, I know, the oncologists are busy, and the oncologists are why I'm here, right? So I've never ever to speak out against oncology. But how do we how do we almost walk to roads with oncology? Right, so how do we say, yes, we want the advancements of science and new treatments and and technology and better quality for patients more quantity of life, but how do we sort of give them the skill set to say there's another treatment? There's, you know, there's first line, second line, third line? Oh, there's a clinical trial, right? And so how do we sort of say you're laughing? You know, that kind of thing. But those things are important, because that's how we make advances. But how do we maybe say, to the patient's health, what's your goal? What do you see for yourself? You what you have, you know, isn't curable maybe right, but doesn't mean you're going to die in three days. That's what I think palliative care people like when I said I was a palliative care nurse, I think people would almost like want to hide from me a little bit. Or I'll often say to friends and family if they asked me a health care question, and like, you know, what kind of nurse I am, you know what I do, right? And they kind of chuckled at me. But so because we just become experts in different kinds of things. But if we could help, I think sometimes with the communication and the conversation, because I've ever experienced things where you know, a patient maybe didn't want to have more treatment, and they stopped having treatment. And they actually lived a lot longer, a lot longer. Because they they responded to what they had. It just takes time. And I think sometimes that's the other thing, too, is that we're always in a hurry. And we want to do this and we want to do this and we want to know what's next. And then if we sometimes just pause, and I'm not a millennial, I always laugh and I always talk about millennials, so forgive me millennials. But I say like, you know, like I used to, we used to take a picture, and we would have a roll of film and we would take it to the lab and then it would come back in a week and then or then they got one hour photo and that was really really amazing, right? But now everything is so instantaneous. And when I'm looking I looked did a lot of teaching in my role to palliative care teaching health care providers, PSWs nurses, even physicians sometimes and like you don't have to be an expert right away or do things instantaneous. The I think and sometimes that pause is what we need, just to see what happens. We're

**Dr. Bill Evans** 15:04

very busy, fast moving society. And I'm sure that also in the Family Constellation impacts, the individual who's ill, and the caregiver and the family around them, because they're all got busy lives. And it's almost inconvenient that one of the members has got sick and maybe is deteriorating could die in the near term. And how do you integrate those things, and you totally abandon what you're doing, which may be just too much for some people. So I've got a big job, it's important, I'm really enjoying my work. I can't give it up for for Dad, mom or my sister, whatever. Because that's we're kind of ingrained that going so fast and doing things in a rapid way. So it makes it even more important, I guess, in our society, that there there be people and structures that can be used as kind of backfill for what seems families no longer do. I know, when I started oncology, I was really impressed with the Italian families, and you go back into the 60s 70s. And he had immigrant families who were so supportive of each other, and they always cared for their loved ones, when they got sick with whatever they just came around them are supportive. And it wasn't my particular experience coming from a different ethnic group. But it seems to me that they had something really special by being so supportive of the members. And I'm afraid our culture's kind of losing that and maybe even those who are third generation, Italians aren't feeling so supportive of their loved ones as, as their parents and grandparents were. But, you know, society, different societies approach illness quite differently. And some are great at supporting and some are, are almost like, I've had relatives say, Doc, why don't you just give the person a shot of morphine? Because you're going to die anyway? Yeah, that's the extreme. It doesn't happen very often. But it does tell you there are people who just see the illness of another human being as an inconvenience to their life, as opposed to really an important person. Yeah,

**Melissa Chadwick** 17:13

like, how do we kind of get to there, right? I mean, you look at the compassionate care benefits, right? So there's like that the benefit that you can have some, you have to take a two week waiting period, through, you know, ei unemployment, and then there's some paid time for people to have and they can be off of work. People could get replaced at work, like I mean, this is a number of years ago, they introduced this benefit, it's probably one of the most underused benefits that we have out there. And that also what happens with that, in my experience is that yes, you need a doctor's note and things like that. But people tap into that benefit way too late. And again, so if I can say anything, palliative care early is better than palliative care late, don't be afraid, I think of of that word. And of the people doing that work, because we support people all we would love to be meeting people when we talk about like a lung cancer patient much sooner in their in their journey. And then being there when they need us more towards the end of the journey, and that we get to follow along. And there's more legacy work that can be done. There's so many things we psychosocial pieces of work that we can do so much so many things that families and people can do. I have an app on my phone called weak croak. And it's I think it's a few I don't know if we're allowed to talk about other things, but it gives you different thoughts and viewpoints about dying. Because there's a culture, I think it's the Bhutan culture that says, if we think about death, it makes our life more meaningful. There's another book that's really good if people want to read, I don't know if you've read it before the physician wrote in the United States being mortal. I don't know if you've read that book, or it's in your library at cat maybe I don't know, you have a library, I think yeah. And he talks about his experiences and things like that, and also help people got into assisted living and safety and stuff like that as well. So it's just very interesting to say, I think that we kind of, again, sort of walk closer to the inevitable unfortunately, all of us are going to that place 100% of us. But if we kind of can walk as companion with it, instead of being afraid of it, I think things would be a bit better.

**Dr. Bill Evans** 19:17

I think we'll take a brief break right now and let people think about those things and write go and write down being mortal. I've read that book. It's definitely recommended as well. And we'll be right back talking with Melissa Chadwick. We're gonna talk about the well designed perfect palliative care service network that you could have. Okay, we'll be right back.

**Narrator** 19:41

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**Dr. Bill Evans** 20:26

We're back with Melissa Chadwick talking about palliative care. And we just before the break, we talked about what maybe would be sort of an ideal way that palliative care services were organized and delivered. And there's so many component parts because there's a part that sort of hospital based where you're integrating with those patients receiving care, be it cancer care, or maybe cardiac failure or stroke care, integrating with with Bose and in a physical place called a hospital, but then there's so much more community wide. And then there are hospices, facilities that people can go to truly at the end of their lives been maybe for quite a long time. They may be there for months, but more commonly, it's a shorter period of time, but they're very homelike environments and and maybe you can you seem to have worked in many of these places. So you're probably the ideal person to talk about them. And then what can bring it all together? How does it come together within a community where we're also fast paced running around like,

**Melissa Chadwick** 21:29

I think what what we're hoping to see as his healthcare is being less a little bit less siloed. And I would say over so I have like a 25 plus year career in nursing and mostly in Home and Community Care, where before it was sort of like, you do this and we do that, like sort of more like a bento box are compartmentalized and sort of siloed. Right? We know they're silos and care. And that one of the neat things I got to do this year, I got to kind of do it twice. Hamilton, we had a compassion communities event. And so it started off small with really just an idea. It was stbd Actually, who, who I worked with who was a visiting nurse at Vonn for years, and then she worked over at Good Shepherd Emanuel house in the hospice, and that she was bringing folks together. I was like, Is this more like parish nursing? I wasn't sure because we did it in a church because churches does have spaces. And so we were just there. And there was, you know, Bob camp, which is now the Camp Care Network. Good Shepherd Emanuel house, myself, Dr. Aaron Gallagher, who's a palliative care physician and family physician and McMaster associate position, she does lots of different roles, funeral homes were there on so it was kind of small, they had like some lunch out and people could come in and sort of see what services some of the agencies were there like Bayshore nursing was there. So it was sort of opened up to anybody who worked in sort of the health care palliative care business, if you will. And then then that's where Aaron met Esther, this is if they've got the story, sort of got it down. And then there were more people sort of saying, hey, well, my my service does this, or they sort of did like us have an environmental scan for being sort of most appropriate with words. And they had we had another event and again, like nobody really owned it. I feel like so Yes, Dr. Gallagher did some of it. And Esther did some of it. And they made a small committee, and one of my colleagues, Bob, he was on that. And they had a Dr. Smith, a winemaker who has been here before on a panel and Pamela Blackwood from McNally hospice, so sort of that Hamilton and greater Hamilton network, folks were there and they had over 40 sort of tables or booths of different groups there. A cap was there. I was there funeral homes. Were there at the corner. Was there refugee like shelter, health, newcomers? Was there Margaret's place hospice, was there Camp Care Network? Was there a manual house was there, the Paramedicine program was there because there's, that's one of the really neat things. I think right now it's emerging is that paramedics doing palliative care, I think that's a really good area where we've got a lot of capacity built in our communities with the Paramedicine program. So all these folks are there. And then there's some folks there, I bought the best sympathy cards I've ever had, like it said, I'm sorry, this sucks right now, you know, kind of thing are the holidays are hard, and I'm sorry, you know, kind of thing like this, you know, so they had some vendors that you could purchase some things as well. They had a panel and then they had like they played music. And I had to teach a class in the middle of it. So I had to go back into one of the rooms with my colleagues and because I do a did a lot of teaching of classes and stuff for palliative care. But it was really it was really amazing. Like I think people got turned away because there wasn't enough parking, believe it or not. That was something they didn't foresee. I think they had up over 120 people attend and they wanted to make sure they were hitting everywhere. So are they hitting Home and Community Care, the hitting hospital, they kind of managed to get to everybody and if they want it to be there. They were there. And it was just a really nice event for a couple hours where they had Yeah, they had some structure With the panel and talk, they had someone who was, I think more marginalized in their health care on the panel to like, and so it was, it was a really good event, everyone like the day after, it's like now what are we going to do? What are we going to do next? Let's have it at the Hamilton Convention Center. Let's have it, let's make it bigger. Let's make it better. Right. Let's invite more folks to that. But it's sort of like I feel like it's like the new power. I think a little bit, if you will, I know I sort of trashed the millennials. But I think what they bring to the table is that it's a collectivism, collectivism. So it's not, you know, the President and CEO of something has to say, this is how it goes. It's a group working together with a common goal. And that's what they do. And that's almost like palliative care people, right. We are a group of people interdisciplinary team working together, trying to make the best of the time that you have left. Now

**Dr. Bill Evans** 25:47

thinking about our listeners out there, so who may be sitting in I don't know, Australia, New Zealand, UK. What's the takeaway out of that it's a crate a very inclusive grouping of people who have a shared interest, but may have different skill sets and different capacity to bring resources into the what we call broadly palliative care supportive care for patients. I

**Melissa Chadwick** 26:13

think a lot of our model comes from the UK. So if we look at like an early identification, and early identification is like a document that we borrowed, caught from the gold standards framework in the UK. So I think that also might sort of trickle over into Australia, New Zealand kind of thing, because we're sort of all the Commonwealth are kind of related, right? We are a bit behind, I would say over here in North America, right? If I've taught tons of students or worked with tons of people that work in long term care, and they've been newcomers to Canada, from the Philippines, or different places in the world. And they're like, death is kind of funny hair. Like we we embrace it more or a Latin America, right? Or Mexico countries, different countries are like, we're okay with this, we celebrate these kinds of things. So for different places, I think in Canada a little bit, we're, we're awesome. But I think we're a little bit behind. But if you look at like I said, like a gold standards framework. And if we look at illness trajectories, just to be technical, we sort of do have a crystal ball, we sort of know how it's gonna go. Not for everybody, but we kind of have an idea, we want to be hopeful, we want to give you the best treatment, we want to meet your goals of care, right. But we know that a person with you know X, Y, Zed type of cancer, or this stage of heart failure, we kind of know how it would look. Do you want to know that? Right? I guess it's also inviting the person. And and I think that's why the caregiver steps important too, right, inviting them to say, Hey, Dr. Evans, tell me about my stage four lung cancer. And it's not even about prognosticating, or how long I have to live. But what's it going to be like the doctors the authority, I guess a bit right, or the CEO is the authority or whatever, right? It's like inviting that person to ask you questions. One of the things we're working on right now is something called serious illness conversations. And as a person who's done palliative care for most of their career, I had this training I did online. And I found it incredibly hard. Because sometimes, when someone's at end of life, we've waited too long. And we have to kind of go charging in there, you know, at the last minute, but serious illness conversations is more about the patient talking about what they want, and what they want to know. And then we have to I feel like I had to kind of sit on my hands a bit. But we use a framework called Wish, worry, wonder. And that really works, I think around so I wish that I had better news to give you around your disease or your disease progression, just say, I worry that if we spend all your time doing tests, and this goes back to the Being Mortal book, right, sending people for tests and doing all these, these chemo therapies and all these treatments and things like that, or, you know, putting in a pacemaker or defibrillator or many doctor's appointments and things like that blood work. And I wonder if we spent the time, the precious time that you have left on things that are the most important to you, if that wouldn't actually be better. So it's not saying you have six months to live, right. It's saying, I just it's just again, language and having those conversations and making it more about the patient and the family and the caregiver. Right. So that I think is something that really is, is I hope it's going to change, folks, and we're looking at primary care like so your family doctor, are they able to have that conversation or that nurse that maybes in the emergency department or maybe on the on the medicine floor or the oncology ward? Are they able to sort of say those things? Palliative care, too, right, is it I think also we need to know what the patients and families want and expect.

**Dr. Bill Evans** 29:50

He touched on something that resonated with me though, the primary care physician should be central in this and unfortunately what has happened Traditionally, in the cancer system, our Cancer Care Ontario in this province has tried to change it. But I think we still have a good way to go is that family doctors would refer to a cancer patient in the cancer center, then the cancer center does its thing, but basically takes over, even sometimes taking over the non cancer related illnesses and prescribing the, the antihypertensives and other things, and leaves the family doctor rowdy, yes, the family doctor gets a note from the cancer state, it doesn't have the same sense of engagement. And then at some point, when the cancer center can do no more, it's almost like they're passed back to the primary care physicians left out of the whole process. And now you look after the sort of death and dying piece, right. And it must be extraordinarily hard as a family doctor to be thrust into that when you've been left out of the trajectory, leading up to it, because you could have had those kinds of wish conversations, right conversations, etc, that would make it easier to have a final kind of conversation with the patient.

**Melissa Chadwick** 31:04

Yeah, that's that's very much I think people's experience, right is that they, you know, they want they're, they're going full tilt at the cancer center, and then that primary care physician does feel a bit left out. And then they're sort of now I have to be do the palliative care of this patient. And that's not my expertise, either, because I'm doing diabetes care and new baby care. And all the primary care has got a big plate, right? They have a huge big plate. But also I went to a conference, the Ontario long term care clinician conference, and they had done another study, again, around people working satisfaction was stuff. So if palliative, if a primary care physician or any physician can have that conversation, everyone thinks, oh my gosh, that's gonna be so depressing. And I'm not skilled at it and those kinds of things. But again, their job satisfaction actually goes up, right. So they felt like they did a good job, they were able to wrap that care around their patient, even if it's a referral to the cancer center, or they have a palliative care team. If they're still involved a bit, and they have some skill around those conversations. It's a better experience for the patient. And the practitioner. So I think that's really important too, is that, you know, oh, well, I don't want to I don't want to do palliative care. I don't want to, there's a team that does that, or whatever. But if we can incorporate that into our practice, and again, serious illness conversations can help people have more of a, I think it's actually the most step by step like a framework on a card, which I'm like, this seems like a bit. It doesn't seem very natural, organic. But I think once you get it down, it really can make a difference to the patient. I'm

**Melissa Chadwick** 32:36

first hearing about critical illness conversations today. Either I'm really a dinosaur, or there may be a lot of people who have not had the experience or learnings about critical illness conversation. So if for any physicians listening to these specialists, or primary care physicians, how would they go about learning about how to do this and develop this

**Melissa Chadwick** 32:59

skill? So right now, we offer education from different places. So it's created and developed. So there's my partners in Waterloo, Wellington that do some education, there's our team in the southwest, it's through St. Joe's that does some education, but Pallium, Canada, if anyone's ever heard of Pallium, Canada, so they have a really good online free module called taking ownership. And they actually purchase the serious illness conversations from BC and that there are courses online that you can take them. And that's where you get you get invited into, like a coaching session. And they're not high cost. And it's something where, so physicians can do that. So if you look at paly, I think it's www.pallium.ca Pallium, covers all of all across Canada, I and my conflict of interest might be as I do teach for them. I'm a facilitator for some of their courses. I'm not here to necessarily promote that I have lots of courses I could talk about and lots of different things. But yeah, that's something that could help physicians that are listening, that serious illness conversation guide is there, you can download it and you can take a course online, I think you get main pro credits physicians, I think that's important. Credit, so there you go. But that taking ownership module, anyone can do it really. So to kind of understand what does a palliative approach look like? And it's about a 45 minute online module with a online facilitator, and you just have to register and then it pops back. Yep. Debbie just did it.

**Dr. Bill Evans** 34:30

So that's very useful information for people to know. Now, one of the we talked about maybe the primary care physicians left out of things. The other key person that's left out is the caregiver, whoever that is, whether it's a spouse or a friend or a neighbor or whatever, who's very close in providing a lot of care. And how did they get included? How could they be included more effectively, I should say, into supporting palliative care measures for a loved one,

**Melissa Chadwick** 35:01

when we look at when I look at teaching folks a when we look at we some look at something called the domains of illness and bereavement and it's it's different boxes around and patient and family are at the center and caregiver actually should be in there too I think and we look at, you know, their disease management, their physical symptoms loss and grief end of life. There's there's a different categories we look at. I think that unfortunately, the pandemic right has had sidelines some of the things that we were doing and in groups, right, so different communities were looking so we had that wonderful compassionate Hamilton event. And I think stay tuned, because more of that will be coming. And I know cancer Assistance Program is linked into that for sure. So there'll be some promotion or things like that coming. I just don't know what it looks like, because they're evaluating it right now. And I know they want to run more events to bring people say, I didn't even know about this. And I didn't know about the service. Sometimes the community hospices, so the hospices have different programming pieces. So the Camp Care, network grief and bereavement pieces there. Wellwood has as programs for kids after school and teach them how to cook a meal and helps them with their homework. And that that in itself helps the sometimes you've got kids that are cast into that caregiver role you look at for grief and bereavement, bereaved families, Ontario has some really wonderful opportunities, also for bereaved and grief, like so that's a little bit different. But you've got that support. And there's caregiver programs all over Ontario. So hospice palliative care, Ontario website has a volunteer training program, and a caregiver support program that you work through modules, and it's online and it's free. There's a publication called the caregivers guide. I have a digitally somewhere here but you can download it for free. And it gives you tips and things about like how maybe to feed somebody, or turn somebody in bed or change the sheets with somebody with an A bed. And the hospices. And I had talked about doing education like that, like almost like a lab, where you would have you know, a hospital bed and sort of like a mock up kind of room? And how would I care for someone who was bedridden? How would I feed them? How can I position them safely? Things like that.

**Dr. Bill Evans** 37:09

sounds so simple in one respect, it's

**Melissa Chadwick** 37:11

not it's not right, sort of like, because there's an appetite for that for those skills, right. And then we don't want to we teach caregivers all the time. I think that's if you look at home care, right? We're often looking at teaching folks had to do things care for themselves, still needing that oversight, and of people coming in to see them. But can we teach them some of the stuff to do themselves? injections and different kinds of things, or sometimes folks are going into the nursing care centers, right, because the because, again, home care and health care right now is sort of at a health care, human resources are not very high, right. We're experiencing low numbers of people in the human resources department. So yeah, there's lots of online resources, I think. And then I think it's but it's also hard sometimes to reach out. So I can definitely give you a list of different kinds of caregiver resources. And again, we've got, you know, hope for the best plan for the rest. And there's events coming for that. There's some really great caregiver education from in the Champlain area that I know they're doing for free. And there's also caregiver education in the Windsor area, a really good program, I can give you links to those kinds of things as well to share

**Dr. Bill Evans** 38:16

and get some of them Yeah, loaded up on the cancer Assistance Program website websites that could be useful then to listeners who are outside of the immediate Hamilton area, might want to tap into it and measure we'll do shameless promotion of the book, hope for the best plan for the rest by Samantha winemaker and Sansa was a podcast we've done previously, we're talking about the book and how it's laid out and the benefits of planning in the face of the serious illness that I understand that book is available globally. So if you're in Australia, you may be able to find it in your local bookstore and hope so anyway. If not, you can find it on Amazon. So find everything on Amazon is one of the things that cancer patients fear, I think the most, besides dying, per se is pain. And then relatives get involved because as pain medication is given, it often leads to people being obtunded. And hence, they look like they're not with us. And so I can't leave them like that and you get in an oscillation. Can you just talk to me and how you would talk to a patient and a caregiver about taking narcotics for a serious amount of pain that you need to control? I

**Melissa Chadwick** 39:32

think that this is a loaded question, to be honest, but that's okay. And I've had experience sort of working with this with people. I think that we also society today unfortunately have an opioid crisis, right so that when folks are prescribed a medication to help with pain, it's for a reason and but then they're also sort of given all this information or Naloxone kit in case they overdose. I think that's a that's a public safety issue more than any anything and, and I get why we have to do that. I totally understand that. But I think I've spent years like talking to people about their pain and from my experience, even working bedside in the hospice, when people were end of life, we use very small doses of medication. We did very good assessment, we made sure they had a breakthrough medication. So we gave them their regular medication, and then we gave them their breakthrough. Again, back to sort of that Dame Cicely Saunders idea, like taking it regularly, not saving it for when you really need it. Dying itself isn't really painful, the actual dying process, but because we have cancer, because we have diabetes, or we had a stroke, or, you know, we have different kinds of issues. That's what causes the pain and so that we want to treat that pain and we want to get on top of it. So we don't have we don't have like, you know, people in horrific pain again, TV movies, right, that sort of idea. And I would say like, also its pain is also not just maybe with use of narcotic or opioid sometimes we have to treat pain differently to by looking at the whole picture, like total pain, emotional pain. I'm always looking at people's mattresses right to make sure they're comfortable as their bed. Okay. You know, is their wheelchair okay? Like, how are they sitting? How are they positioned? If they're, if they're still getting up, things like that. So what else can we do for pain, right? Distraction, music, music, therapy, art therapy, all those kinds of things are kind of out there. But I think people yes are worried about being in pain. And that we know that up front. And we have people trust us a bit. You know, but there's lots of people that don't, I guess there's lots of rules on pain medication, but also to don't be afraid to take it right. Also, our pain medication helps with breathlessness and I think for many years, you and I probably worked around the same time we used to give sleeping pills at bedtime, people would fall out of bed and we used to give that pill Ativan is what I'm talking about when people were anxious or breathless, but really our morphine or hydromorphone is a better medication for that. And so and if we again start earlier, we're looking at the whole picture holistically. Maybe there's some like psychological pain that we're we're we can treat that will make that physical pain less. Yeah, that's what that's what I think I could talk about pain to you all day.

**Melissa Chadwick** 42:23

That was a very good, loaded, okay. It really wasn't trying to load No, no, it's okay. It's okay. That's okay. Well, I think we're gonna wrap up in a moment, but I want to give you a chance, thinking about people listening out there, what, maybe two or three key messages you'd like them to take out of our conversation today?

**Melissa Chadwick** 42:42

I would, I would say, don't be afraid to ask questions, I find that people sometimes feel like the doctor or even the nurse or the nurse practitioner is the authority. And we don't know everything. And we need to spend more time I think asking people questions about less clinical questions, and more about what's really important to them. I think that's really important. I think the question you can ask any healthcare provider, when you have a serious illness or life limiting illness, because, oh, I know from fact sheets over about 70% of people don't ask the questions. Where am I in my journey? Or where is my loved one in the journey? Are we in the in this world from Sammy and CN? Beginning, middle, or end? And so am I more towards the middle? And my more towards the end? I think that's it's almost like no one's really offended by that. Because it's like a childhood story, right? If you think about like Jack in the Beanstalk, or a Little Red Riding Hood, Beginning, middle end of the story. And I think that's a really, I think that also, healthcare providers can answer that question, right, I think you're more towards the middle, I think you're more towards the beginning. So I think that's a really good way I use, like I said, language matters. And that's really important. And I just think that if you, if you get referred to a palliative care team, don't be afraid of those people. And we're, we're usually pretty nice. We were there for a reason, I think, and that most of the folks that I've worked with are taught always, they have a story, we all have a story, right? And so that's where the compassion and the empathy comes in. For the most part. Again, we pick that specialty over say, emergency medicine or, you know, or labor and delivery wouldn't catch me dead working in like a department like that was too frightening for me. And when I was in school, you know, that kind of thing. So don't be afraid, I guess. Don't be afraid. Don't be scared and don't ask questions at it's not we don't know everything. When we don't know you, you know you and you know your family. Don't be afraid to ask the questions to us.

**Dr. Bill Evans** 44:44

I think that's a very good last point to end to end with because it applies not only to palliative care situations about the whole of your illness about every aspect of it, don't be hesitant to ask questions, and maybe to add a Corolla already to it is have someone with you who is another set of years and maybe has a pencil in hand and can write down the answers because oftentimes, when you're receiving information in the context of a cancer center, there's a bit of an emotional overload. And you may not hear all the answer email here, as cleanly and accurately as it was intended. So might just be another little thing to think about. As we wind up today's podcast, I'd really like to remind our listeners that they can listen to a lot of previous podcast by visiting the cancer Assistance Programs website, which is cancer assist one word.ca. I think there are 50 podcasts there now that are covering a wide range of topics, a lot of different tumor types, how they're treated, but as well, a lot of the supportive care services that are really important and integral part of good quality cancer care, and we're blessed to have a lot of them in the Hamilton area. I hope in the area where you live and receive care that you have similar, high quality sort of care services. I just like to thank Melissa Chadwick. For all your insights and thank you palliative care today. You've been a great person to have conversation with and I think our listeners will have derived a lot of benefit from what you've said. So thank you very much. Thank you.

**Narrator** 46:22

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